



## **DEPARTMENT OF HEALTH AND HUMAN SERVICES**

### **Health Resources and Services Administration**

#### **Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children**

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS).

**ACTION:** Notice.

**SUMMARY:** In accordance with the Federal Advisory Committee Act and the Public Health Service Act, this notice announces a public meeting of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC or Committee). Information about the ACHDNC and the agenda for this meeting can be found on the ACHDNC website at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

**DATES:** Tuesday, August 30, 2022, from 10:00 AM to 2:00 PM Eastern Time (ET) and Wednesday, August 31, 2022, from 10:00 AM to 1:00 PM ET.

**ADDRESSES:** This meeting will be held via webinar. While this meeting is open to the public, advance registration is required.

Please register online at <https://www.achdncmeetings.org/registration/> by the deadline of 12:00 PM ET on August 29, 2022. Instructions on how to access the meeting via webcast will be provided upon registration.

**FOR FURTHER INFORMATION CONTACT:** Alaina Harris, Maternal and Child Health Bureau, HRSA, 5600 Fishers Lane, Room 18W66, Rockville, Maryland 20857; 301-443-0721; or [ACHDNC@hrsa.gov](mailto:ACHDNC@hrsa.gov).

**SUPPLEMENTARY INFORMATION:** ACHDNC provides advice and recommendations to the Secretary of HHS (Secretary) on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. ACHDNC reviews and

reports regularly on newborn and childhood screening practices, recommends improvements in the national newborn and childhood screening programs, and fulfills requirements stated in the authorizing legislation. In addition, ACHDNC's recommendations regarding inclusion of additional conditions for screening on the Recommended Uniform Screening Panel, following adoption by the Secretary, are evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA, pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering non-grandfathered group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

During the August 30-31, 2022, meeting, ACHDNC will hear from experts in the fields of public health, medicine, heritable disorders, rare disorders, and newborn screening. Agenda items include the following:

- 1) A presentation on phase one of the Krabbe disease evidence review;
- 2) A presentation and Committee discussion on the infant formula shortage;
- 3) A presentation and Committee discussion on advancing the newborn screening system;
- 4) A presentation on the Long-term Follow-up for Severe Combined Immunodeficiency and Other Newborn Screening Conditions Program; and
- 5) Workgroup updates.

The agenda for this meeting does not include any vote or decision to recommend a condition for inclusion in the Recommended Uniform Screening Panel. As noted in the agenda items, the Committee will hear presentation on evidence review of Krabbe disease, which may lead to such a recommendation at a future time.

Agenda items are subject to change as priorities dictate. Information about ACHDNC, including a roster of members and past meeting summaries, is also available on the ACHDNC website.

Members of the public also will have the opportunity to provide comments. Public participants may request to provide general oral comments and may submit written statements in advance of the scheduled meeting. The Committee will honor oral comments in the order they are requested and may be limited as time allows. Participants who wish to provide a written statement or make oral comments to ACHDNC must submit their request via the registration website by 12:00 PM ET on Wednesday, August 24, 2022.

Individuals who need special assistance or another reasonable accommodation should notify Alaina Harris at the address and phone number listed above at least 10 business days prior to the meeting.

**Maria G. Button,**

*Director, Executive Secretariat.*

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